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ABSTRACT

This practicum study assessed the formation of The Western Pennsylvania Fetal Alcohol Support and Information Network, established to provide assistance to foster and adoptive families of children with Fetal Alcohol Syndrome and Fetal Alcohol Effect (FAS/E). Priorities for the network were: (1) increasing awareness and knowledge of FAS/E issues among foster and adoption agency staff; (2) providing information to families with an individual with FAS/E; (3) establishing a system of mutual support for these families; and (4) identifying methods of continuing these services after the end of the practicum. Staff workshops focusing on the developmental course of this disability and printed information packets were used with four foster and adoption agencies. Families with FAS/E individuals were contacted through parent newsletters, newspapers, and existing parent groups. Host FAS/E families were identified to organize informational workshops in their communities to be conducted by the author. Results suggested that all workshop participants demonstrated increased understanding of FAS/E. Information packets were mailed to 48 adoption and foster care agencies in the area; several had copied and distributed them to staff. Although 17 families were identified for the network, parent meetings were not successful because most families were not interested in attending them. Including parents at staff meetings, distributing a newsletter, and creating linkages between individual families were used to meet parent needs for information and support. Several funding possibilities were identified for continuing the network. Appendices contain instruments used in the study. (Contains 21 references.) (KDFB)

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Establishment of Fetal Alcohol Support and Information Network of Southwestern Pennsylvania: A Response to the Expressed Needs of Foster and Adoptive Parents

by

Mary Patricia Zebroski

Cohort 10F

A Practicum Report

Presented to the Master's Program in Life Span Care and Administration

in Partial Fulfillment of the Requirements

for the Degree of Master of Science

Nova Southeastern University

1996

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July 5, 1996
Date

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Signature of Student

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Aug 7, 1996
Date

Mary Patricia Jakoski
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Abstract

Establishment of Fetal Alcohol Support and Information Network of Southwestern Pennsylvania. A Response to the expressed needs of foster and adoptive families. Zebroski, Mary Patricia, 1996. Practicum Report, Nova Southeastern University, Master's Program for Life Span Care. Descriptors: Fetal Alcohol Syndrome/Fetal Alcohol Effect/ Adoption/Foster Care/Disability Support Networks.

This report describes the formation of The Western Pennsylvania Fetal Alcohol Support and Information Network. The Network was established to provide assistance to foster and adoptive families of individuals with Fetal Alcohol Syndrome and Fetal Alcohol Effect. Following a telephone survey of fifteen such families, four priorities were established: Increasing awareness and knowledge of FAS/E issues among foster and adoption agency staff, providing information to families that include an individual with FAS/E, establishing a system of mutual support for these families, and identifying a method of continuing these services over an extended period of time. The report discusses several approaches used in implementing these goals, analyzing their relative success. It also includes information on several unexpected positive outcomes which were a direct result of the efforts of this program.

Appendices include surveys, public service announcements, and sample information packets.

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Chapter 1

Introduction and Background

Setting in which the problem occurs

The setting for this practicum is the foster care and adoption community of southwestern Pennsylvania. Like southwestern Pennsylvania itself, these families are enriched by their diversity. They are multicultural, and can be found in urban, rural, and suburban settings. Despite their many differences, this community shares a common issue, the challenge of raising children born to someone else! Among these families is a subgroup who face the additional challenge of raising children whose lives have been forever altered by prenatal exposure to alcohol. These children face a lifetime disability that is not clearly understood by the general public or by many of the systems intended to support and meet their needs.

This project was conducted as a cooperative effort of two agencies: a small family support agency for foster and adoptive families, and a large multiservice adoption exchange. The first, of which the author is founding director, was created in 1995 as a resource for foster and adoptive families and the agencies who work with them. This agency currently provides three types of service: professional training, case management and consultation. Training opportunities have been directed toward foster and adoption agencies and are provided on a fee for service basis. Case management services, which are funded through Medical Assistance are provided to children whose disabilities require an intense level of service coordination and professional intervention. Consultation services have been utilized by both agencies and families. Agencies are billed an

hourly rate for consultation services. Consultation services are provided to families at no charge. Currently, this agency has a client base of fifteen families. Eleven of these families are adoptive families, two are kinship foster parents, and one is a non relative foster home. Seven of these families include children with Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effect (FAE). In addition, the agency provides case management services for a seventeen year old paraplegic who lives with his stepfather.

There is diversity even among this small group of clients. Both kinship foster parents are single African American women who are raising their grandchildren. The stepfather of the seventeen year old is a Caucasian single parent. All other parents are Caucasian couples. Their children, however, represent different ethnic groups. They are American born Caucasian, African American, Cambodian, and Russian. The families reside in urban, suburban and rural settings in a six county area.

All but one of these clients were self referred. One family requested assistance resolving a conflict with the foster care agency who had placed their child with them. The father of the seventeen year old requested assistance in finding transitional services for his son who had been involved in an automobile accident. The other thirteen families approached this agency because of educational and behavioral difficulties they were experiencing with their children.

Because of the small scope of this agency, the author worked with another, more established social service agency on the Pittsburgh area to complete this practicum. This nonprofit agency, which is a consortium of more than 50 adoption agencies and adoptive parent groups, was established in 1982 as a source of information and referrals for all involved in the adoption

process. It maintains a regional adoption exchange, linking waiting children with adoptive parents throughout Pennsylvania. It provides information and referrals to families who are beginning the adoption process, as well as support for families whose adoptions have been finalized. In addition to monthly seminars for both parents and professionals, the agency has published a series of pamphlets on topics of interest to adoptive parents and community professionals. This agency also has a state contract for recruitment of families for older and minority children, as well as a federal grant to research the long term effectiveness of special needs adoption. Additional income is derived from grants and contracts with local county child welfare agencies.

Since its beginning in the early eighties, this agency has assisted in the placement of over 3,000 children, ranging in age from infancy to seventeen. All of these children had been identified as "special needs" by their referring agencies. The term special needs is used to describe any child who is considered difficult to place for adoption. This includes minority children over age four, Caucasian children over age eight, children of all ages with disabilities, and sibling groups of three or more. Over ninety five percent of the children listed on the agency adoption exchange were referred by child welfare agencies, who had assumed custody of the children because of the parents' inability or unwillingness to provide for the health and safety of the child. The number of children in this population who suffer from FAS or FAE is not documented, but Sherry Anderson, Program Director of this agency, estimates that maternal drug and alcohol abuse are included in the social histories of more than 75% of the children placed for adoption (Personal communication. January, 1996).

Who Adopts Special Needs Children?, a publication of the National Adoption Center (1988),

profiles the statistically typical adoptive family of a special needs child Families who adopt special needs children are likely to be middle or lower middle class economically They are most likely to reside in a small town or rural area and have traditional values and religious attitudes In most cases they are experienced parents, often having raised more than one child before adopting Most adoptions are still by couples, but single parent adoption is becoming more common, especially for children with severe disabilities and teenagers Adoptive parents are more likely to be Caucasian, but the number of African American families who choose to adopt is increasing steadily (Anderson Personal communication January, 1996)

While this practicum was sponsored by the agencies described above, the real setting for this effort was in the homes of the adoptive and foster parents who confront the challenges of parenting difficult children on a daily basis This program was designed in response to the expressed needs of these families

The student's role in the setting

The author of this report is the founding director of the smaller agency involved in this study, having created it after working nine years for a special needs adoption agency Five of those years were spent as the manager of post adoption services During this time, she became increasingly concerned about the lack of supports available to families after their adoptions were finalized In addition to her professional experience in adoption and foster care, she is also the adoptive parent of five children, two of whom have Fetal Alcohol Syndrome

The author is also a former board member and employee of the cooperating agency, and

maintains on an ongoing professional relationship with its administration and staff. She has served on the program committee, and has provided professional training for agency staff. During the duration of this practicum, her exclusive responsibility at this agency was the development of resources for families that include children with Fetal Alcohol Syndrome and Fetal Alcohol Effect

Chapter II

The Problem

Problem Statement

Many children currently in foster and adoptive families are suffering from Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effect (FAE), disabilities with unique physical, educational, and behavioral characteristics. With early diagnosis and appropriate intervention, children with FAS or FAE can experience some level of independence and self sufficiency in adulthood. As this chapter will discuss, however, many adoptive and foster families in Western Pennsylvania do not receive the information and support essential to helping their children with FAS/E succeed. Parents reported during the initial stage of this program that most professionals who work with their children are not familiar with the specific characteristics of FAS/E. As a result, these children may be at risk for severe behavioral problems, school failures, and placement disruptions. Many parents also report that they have no contact with other parents of children with FAS/E. This makes it impossible for parents to learn from and support each other.

The goal of this practicum was to make information about FAS/E and its treatment implications available to parents and professionals. In addition, it was intended to create a framework for sharing information and support among parents of affected children.

Documentation of the Problem

Documentation of this problem was lengthy in that it required three steps. First, it had to be established that all adoptive and foster families need both clear information about the children they are parenting and ongoing support if they are to remain intact. The second issue for documentation was that prenatal alcohol exposure creates difficulties that require specific type of intervention. Finally, documentation was necessary to show that little support for families of children with FAS/E is currently ava' ' le in Southwestern Pennsylvania.

Need for postplacement support. Each year tens of thousands of families across the United States add to their families through the finalization of an adoption. Contrary to public perception, the "adoption story" does not end when the newly created family exits the judge's chambers. Many of these children have come to their adoptive families after years of foster or institutional care and with significant histories of neglect and abuse. For these children, the finalization hearing is just a mile marker in the lifetime journey of adoption. Their fellow travelers are hundreds of thousands of children who move through our foster care system. Although the actual number of children currently living in foster care is not systematically tabulated, the Select Committee on Children Youth and Families projected in 1989 that over 550,000 children acro:s the United States would be in foster care by the end of 1995. Over 55% of these children can expect to be in two or more placements, 8% in more than six different families. (National Commission on Children, 1991). The "baggage" these child·en carry on their journey can be tremendous. Attachment disorders, unresolved anger, and Fetal Alcohol Syndrome are just a few of the heavy burdens that these children now carry into the lives of their new families. While little

research is available to document why children move from foster home to foster home, adoption literature is overwhelming in its recognition of the importance of complete information and long term support in maintaining placements. Barth and Barry (1991), in an important study of adoption and disruption, interviewed 120 families who had adopted special needs children. Among families interviewed who stated that they had not received full information about their child's disability or social history, the disruption rate was an alarming 46%! Families who believed they had been given more complete information experienced a disruption rate of 16%.

Other studies on adoption and disruption support the importance of accurate information in maintaining adoptive placement. In addition, while a variety of reasons for disruption, such as extended family pressure or sibling conflicts, were identified, "there was remarkable concurrence among the studies ... that one of the surest factors in preventing disruption is the provision of continuing support services beyond the point of legal consummation" (Watson, 1991, p. 7). Elizabeth Cole (1986) suggests a minimum of three types of postlegalization support that should be made available to every adoptive family: education, counseling, and crisis intervention.

Other agencies, such as Project STAR, located in Allegheny County, Pennsylvania, believe postlegalization services must extend to the community in which the child lives. According to director Susan Davis, STAR postlegalization staff work directly with the schools or other professionals serving both child and family (personal communication, March, 1994). Research supports this philosophy. Barry and Barth (1991) suggest the following:

> Typical postplacement services that are limited to office or kitchen counseling and fail to explore the child's broader work suggests that many social workers do not recognize or

know how to respond to the importance of schools in the lives of parents and children. Collaborative training with educators, school social workers, and school psychologists would benefit adopted children (p. 191).

Kenneth Watson (1991), chair of The Adoption Task Force of the Child Welfare League of America, believes that agencies have a responsibility to the children and families with whom they work to ensure that knowledgeable therapists, behavior management specialists, and special education coordinators are available throughout the lifetime process of adoption. While some agencies may argue that the provision of long term support is beyond the scope of their programs, none will disagree with the importance and positive impact of such support.

Specific FAS issues. Lack of information and support to a family raising a child with FAS/E can complicate an already difficult task of integrating a new member into an existing family. In her landmark article for The Atlantic Monthly, "Problem Adoptions", Katharine Davis Fishman (1992) succinctly summarized what families and agencies have found to be true. "When adoptions come to grief, it is often from a disparity in expectations: either the parents expected something the child can't deliver, or the child delivers something the parents didn't expect!" (p. 42). This is never more compelling than in the case of a family who has adopted or is providing foster care for a child with FAS and who has been given inadequate information about its impact. Diane Malbin, (1993) well known author and parent of a child with FAS states simply, "Trying to raise a child with undiagnosed FAS is like trying to get around Cincinnati with a road map of Denver. It's a good map, and it works in another city. But the streets just dead end, or end up in places you don't expect" (p. 253). Even after a child has been diagnosed with

FAS/E, parents may not be aware of the specific behaviors accompanying this diagnosis. They may still be unprepared to deal with the needs and challenges of the child they are raising. In order to recognize the importance of information and the nature of supports that must be made available to families of children with FAS, it is necessary to first understand the pervasive nature of the disorder itself.

Fetal Alcohol Syndrome is a collection of symptoms that can result when a developing fetus is exposed to ethanol, the primary intoxicant in alcoholic beverages. Since the fetus lacks the enzyme alcohol dehydrogenase, which metabolizes alcohol, alcohol can quickly reach toxic levels in the fetus. Complicating this is the immaturity of fetal liver and kidneys, which are unable to quickly break down and excrete the alcohol (Soby, 1994). The resulting prolonged exposure to a depressant can have a profound impact on the developing fetus. FAS is chiefly characterized by abnormalities in three areas: the face, somatic growth, and the brain.

To qualify for a diagnosis of FAS, an individual must present a facial structure that is specific to the disorder. The face of FAS is characterized by a series of abnormalities that form a "T" within the face. The horizontal axis is formed by the eyes. In a typical facial structure, the length of each eye slit is roughly equivalent to the distance between the inner corners of the eyes. In a child with FAS, the distance between the eyes may be up to 50% greater than the length of the eye openings. In addition, some children with FAS have epicanthal folds (skin covering the corner of the eye) or ptosis (drooping) of the eye lid. Along the vertical axis, consideration is given to the nose, midface, and lips. In FAS the nose is slightly shorter than the norm in comparison to midface length and the area adjacent to the nose may have a flat appearance. The

philtrum is shallow and the upper lip is thinned. The facial characteristics of the vertical bar become less obvious in adolescence (Clarren, Aldrich, and Ashley, 1993). To assist in the diagnosis of an adolescent or adult, a photo from early childhood may be necessary. Unfortunately, many children in foster care or adoption do not have early photos available to them.

Somatic growth deficiencies are generally considered to be the least reliable indicator of FAS. They can be used to support a diagnosis, but normal growth pattern does not rule out a finding of FAS. Children with FAS usually have low birth weight and remain below the tenth percentile for both height and weight until puberty. At this time, a growth spurt may improve the height centile. Growth deficiencies in FAS are not associated with poor nutrition or hormone deficiencies, so are not generally treatable.

The last diagnostic criteria for FAS is a specific pattern of brain damage. Evidence of brain damage is not simply inferred through observation of affected individuals. Autopsy studies of children with FAS reveal clear and extensive neurological damage (Clarren, 1986). Children who have been diagnosed with Fetal Alcohol Effect do not have the facial or growth abnormalities associated with FAS, but have experienced the brain damage and demonstrate its effects.

Damage to the brain may be structural, neurological, and/or behavioral. Structural abnormalities are least common. They may include microcephaly, hydrocephalus or structural anomalies of brain matter. Neurological damage includes a number of symptoms. These may be abnormal EEG patterns, tremors or poor coordination, abnormal muscle tone (hypertonia or hypotonia) and vision and hearing deficits (Clarren et al, 1993). Parents should be aware of all of

these possibilities, since early intervention and medication may ameliorate these conditions

" The behavioral outcomes of alcohol exposure are of greatest long-term significance for the affected individuals and for society which must provide educational, medical, and social services" (Coles, 1992, p 13) The behavioral implications of Fetal Alcohol Syndrome can be a source of frustration to many parents Barth and Barry (1988) report "The child is an active partner in an adoption, and the child's behavior is a strong determinant of the placement's viability" (p 132) Many of the behavioral and educational difficulties presented by children with FAS/E can be perceived as willful disregard for parental values and expectations Others are more clearly recognizable as symptomatic, but are equally frustrating They include, but are not limited to, the following

1 Reduced IQ performance Many individuals with FAS fall within the range of mental retardation, although IQ in the low average or borderline range are common This places many children with FAS/E in a grey service area, unserved by the mental retardation system and often not well served in the special education system Parents are often frustrated in finding therapists or educational programs that meet the needs of their children

2 Attention deficit disorder, with or without hyperactivity Families whose emotional commitment to the child is just developing often find the activity level of the ADHD child very difficult to accept (Parent, personal communication, January 1996) Children with ADHD are often intrusive and can be both destructive and aggressive Children whose attention deficits are not accompanied by hyperactivity can go unnoticed and unassisted in classrooms for years A child who has FAS/E is not a good candidate for inclusion, requiring small classes with fixed

routines for optimal learning. Classroom adaptations that focus on restructuring the environment seem to have the most favorable impact.

3. Learning disabilities. Many people have a learning disability in one or two areas. Children with FAS seem to have processing deficits in all areas. They have trouble recording, interpreting, storing, retrieving, and using information. Many children will function well one day and poorly the next. (Morse, 1993, p. 32).

Arithmetic is often the most problematic area and as a result many children will never learn to tell time or make change. These basic skill deficits compromise the ability to function socially. Even for children who are able to read a clock, the concept of time remains vague. One family tells of their child sitting home from school all day, because she was not looking at the clock when her departure time of eight o'clock arrived. She chose to sit home waiting for eight o'clock to come around again rather than leave at 8:03. Parents who do not understand how this behavior is a function of a disability would see it as irresponsible, noncompliant, or defiant. A family with an understanding of FAS would have a protocol in place should the child miss her departure time. An adolescent who misses curfew because he has no concept of travel time from a friend's house to home is just as frustrating as the adolescent who consistently misses curfew because he chooses to be noncompliant. The parent, however, must respond to these two situations quite differently. Even the most understanding and supportive of parents, however, can be worn out by constantly having to predict and plan for every possible outcome.

4. Speech and language delays. Although children with FAS/E are usually delayed in acquiring speech, they become quite "chatty" in early childhood. Often times they impress casual

acquaintances with their vocabulary and inquisitive nature Unfortunately, this seeming verbal skill camouflages lack of depth in conversation and difficulty recalling stories or events in any detail The questions asked by children with FAS tend to be repetitious and center on a few perseverating themes

5 Problems with reasoning and judgement Parents of children and adolescents with FAS/E find this aspect of FAS to be especially troublesome Kodituwakku (1992) reports that children with FAS experience unusual difficulty with problem solving, generalizing information, and controlling their own behavior Difficulty in learning from experience and planning for the future was also noted

> Observations by individual clinicians suggest additional behavioral problems, including failure to learn from mistakes, lack of judgment, lack of remorse for misbehavior, lying, immature behaviors, persistent sleeplessness, extreme mood changes, unusual aggressiveness, and a wide variation in learning abilities at different times (Morse, 1993, p. 26).

A family who understands the nature of FAS/E is better able to provide what their child needs Predictable routines, clear expectations, and supervision beyond that dictated by chronological age are all necessary parenting demands Because of the child's appearance of competence, parents are often viewed by unknowledgeable professionals as overprotective or unduly rigid Without support, these parents can become frustrated and less effective as they find themselves dealing not just with their child's disability, but a lack of understanding on the part of service providers

In their training manual, Fostering Families, Schatz and Mallea (1992) discuss the importance

of support for parents caring for children with FAS.

> Parents need strong support systems and good self care practices while caring for FAS children. A support group for caretakers of FAS children is ideal. Parents need a strong supportive relationship with social service workers. Workers need to be knowledgeable about FAS and serve as advocates in securing the necessary financial, medical, and educational assistance needed by these children. Most important, parents need to take care of themselves emotionally and physically. (p. 18)

The demands of caring for a child with FAS/E can be draining to any adult. A parent who hopes to do more than simply care for his child, and works constantly toward the best possible outcome for the child, faces a tremendous challenge. Adoptive and foster parents who take on that challenge need and deserve support throughout their endeavors.

Lack of available supports in Southwestern Pennsylvania. The author's prior experience in providing postplacement services to adoptive families suggested that the necessary supports and information were not readily available to families of children with FAS/E in Southwestern Pennsylvania. No documentation of this fact was clearly available, however. It seemed most appropriate to approach families directly to determine if their needs were being met.

The confidential nature of foster care and adoption made the identification of families of children with FAS/E difficult. With the cooperation of the adoption exchange, however, an introductory letter requesting contact from parents of children with FAS/E was mailed to all families on their current mailing list (Appendix A). The list consisted of almost three hundred families, some of whom had already adopted and some of whom were waiting for adoptive placements. This list did not identify the status of each family. The introductory letter was also

distributed through a local foster parent association to an additional 27 families. It could not be determined how many of the foster and adoptive families included a child with FAS/E.

The letter invited parents of children with FAS/E to participate in a phone interview to discuss the information and support they were receiving. Fifteen parents responded to the letter, agreeing to participate in the interviews. Thirteen were adoptive families, two were foster families. The author believed this to be an acceptable response.

The interview was conducted in three parts. (Appendix B) First the author, who conducted each interview, explained the purpose of the survey, both as an information gathering tool and a graduate school project. Confidentiality was assured. The main body of the interview focused on three areas: information made available before placement, support services that have been used since placement, and anticipated needs. The interview ended with the author thanking the participant and offering to share the results of the study with participants if they wished. Each was also asked if they would like to be placed on a mailing list for further communications on this issue. They were assured that their names would be maintained separately from their interviews, so specific responses would be known only to the interviewer/author. Fourteen families agreed, giving their full names and addresses. One parent did not want to receive additional mailings, but was open to phone contact. Fifteen responses is a small sampling of the number of foster and adoptive families in Southwestern Pennsylvania that include a child with FAS/E and certainly cannot be used to draw any global conclusions. However, the concurrence among those interviewed was striking. Their responses formed the starting point from which this project was developed.

The response to questions regarding preplacement information revealed that only three families were aware of their child's disability before he or she joined the family. Of the twelve who were unaware, one believed that the placing agency deliberately withheld information regarding the possibility of FAS out of concern that the family would not then accept the child. Two families recalled the possibility of FAS/E being discussed, but felt the agency had minimized its likelihood and significance. Five other families were given no information about possible FAS, but most did note that the behavioral problems which they now know to be elements of FAS were discussed by the agency before placement. The other children had been placed as infants or toddlers, with no previously reported delays or difficulties.

The author asked the families if the placing agencies had offered additional information on FAS/E after the diagnosis was made. One adoptive family reported that the placing agency had sent a handout on FAS at the family's request. The foster families expressed frustration that they were never given adequate information to meet the needs of their children and had in fact been reprimanded when they asked if FAS was a possibility. According to the foster care agency, sharing this information constituted a violation of the confidentiality of the birth mother.

Four families had done extensive research on FAS/E on their own, but most indicated an ongoing need for more information and guidance. Several parents reported local libraries had limited information on FAS/E and all agreed social services agencies had provided minimal enlightenment. Since additional information on FAS/E was later identified by parents as their greatest need, this inability to locate information was viewed as a significant issue by the author.

The second part of the interview discussed services that families had used. The most

commonly used were special education and behavior management consultants. Eleven of the fifteen families had children currently in public schools. All were receiving some type of special education services. Two children were being homeschooled, one for religious reasons and one because the parent did not believe that public school met her child's needs. Two children had already graduated from high school. Of the eleven children in school, two had used educational advocates through The ARC (formerly known as The Association for Retarded Citizens) and their adoptive parents felt that their children's educational plans were adequate. Both foster parents and one adoptive parent had enlisted the aid of the placing agency in developing a school program for their children. All of the families who expressed dissatisfaction with school programs believed that a lack of understanding of FAS by both themselves and their children's teachers were significant barriers to learning.

Seven of the fifteen reported using behavior management consultants provided by county Mental Health/Mental Retardation programs for their children, with none reporting any degree of success in changing problematic behaviors. Other services which families had used include respite care, family counseling, and individual therapy. A recurring theme throughout the interviews was the families' difficulty in finding these services. Families repeatedly stated that they had struggled for long periods of time in their search for support and assistance. Seven families stated that their child's placement in their home was seriously jeopardized by his or her behavior. One family had placed their adopted child in foster care for a period of six months while they reassessed their ability to continue parenting him. He returned home after this period of time, but the adoptive family continued to struggle with his behavior. One foster family had a child removed from their

home due to behaviors associated with FAS.

The third portion of the interview discussed families' projected needs. Responses varied, but several issues were included in the majority of responses. All but one family expressed a desire to be in touch with other parents of children with FAS/E. Questions about the value of a support group elicited mixed reactions. Most families said they would probably attend meetings if the were held in their community, but were less willing to travel any distance to meet.

Fourteen parents expressed a need for additional information on FAS/E. Several parents asked for printed information to share with their children's teachers and/or therapists. One parent felt she had a fairly good understanding of her child's disability, but lacked the ability to explain his unusual behavior to her extended family.

Other needs expressed were a function of the age and level of disability of the affected child. Parents of elementary school aged children expressed a need for knowledgeable behavior management specialists and therapists. Parents of adolescents and young adults were predictably more interested in job coaches and independent living programs.

The age range of children represented in the survey raised the issue that responses related to placement preparation may no longer be accurate. Since many of the children had been placed with their families years ago, the possibility existed that more information and support was currently being given to new foster and adoptive families. To determine if this might be the case, a second survey was conducted among practicing case workers (Appendix C). The author distributed this survey to colleagues attending a training conducted by the Pennsylvania Office of Children, Youth, and Families for area foster and adoption agencies. The instructions

accompanying the questionnaire asked that the senior staff person in attendance from each agency respond on behalf of all staff present from that agency and submit one completed form per agency. Representatives of eight foster and adoption agencies were in attendance and a response from each was submitted. Admittedly, this was a small percentage of the number of foster care and adoption agencies in Southwestern Pennsylvania. Based on her years of working in the field, however, the author believed that it represented a typical cross section of public and private agencies.

The survey consisted of three questions. Caseworkers were first asked if information about FAS/E was included in their general parent preparation program. Two reported that the topic was routinely included, but limited time was allotted to it. A third agency reported that they have scheduled a workshop on FAS/E for foster families as part of their ongoing foster parent certification. The remaining five agency representatives stated that they did not routinely include information on FAS/E in their parent programs.

The second question posed to agency representatives was whether they or any agency staff had received training from their agency on FAS/E. Only one agency had offered such staff training.

The third question concerned postplacement supports offered to families of children with FAS/E. None of the agency representatives reported that their agency offered any type of support or expertise specific to this disability.

Although placement agencies did not appear to offer much support to families, there was still a possibility that such services might be available in another service system. The mental health and

mental retardation sector were possible resources. The Mental Health Association and The ARC chapters in two local counties were contacted by phone. Each was asked if they had any print information on FAS/E which could be mailed. They were also asked if they had a staff person who was knowledgeable about FAS/E to whom referrals could be made. The ARC acknowledged the need for services, but offers none specific to FAS/E. Their primary efforts in this area are directed toward awareness and prevention rather than support. The Mental Health Association also has no programs or information to offer, although they are aware of a National FAS/E Clearinghouse to which they have referred families. Besides the inability of these programs to offer information, no support group or information source for FAS/E is listed in Where to Turn (1994), a United Way publication which lists social service agencies, advocacy organizations, and support groups in eleven counties in Southwestern Pennsylvania.

To assess the availability of services to families and individuals affected by FAS/E, this author had conducted three surveys: phone interviews with adoptive and foster parents of children with FAS/E, a questionnaire distributed to agency representatives, and a phone interview with key service providers in the community. The results of these efforts would seem to document the lack of services for foster and adoptive families of children with FAS/E in Southwestern Pennsylvania.

Analysis of the Problem

Several factor may contribute to the absence of information routinely available to foster and adoptive parents of children with FAS/E. Agency staff may be unfamiliar with the characteristics

of FAS/E, resulting in children being placed into families without being appropriately diagnosed. Even when agencies are aware of the disability, some caseworkers may unwittingly minimize the long term effects of this problem when discussing children with prospective parents.

As reported, few agencies provide training specific to FAS as part of their preparation and homestudy process. It is important that parents of children at risk for FAS/E be well prepared for the unique learning and behavioral characteristics of this disorder.

Both foster and adoptive parents may struggle for years with children whose needs cannot be met in traditional child serving systems. In the case of foster parents, information about maternal drinking habits is often withheld due to reasons of "confidentiality." If the child's history with the family is short, they may be unaware of behavior patterns that might signal FAS/E to anyone with knowledge of the disability and the child's history. If the child has been in multiple placements, information that might help in a diagnosis and treatment may be lost, or confused with issues related to multiple placements. In the case of an adopted child, agencies may withhold or minimize information regarding the possibility of FAS/E when the child is presented to the family out of concern that the family will decide not to accept the child. In addition, the parents' elation over finally having a child placed with them may cause them to minimize the same facts when making their decision. Several of the families interviewed for this study who were made aware of their children's birth mothers' history of drinking stated that they grossly underestimated the impact of prenatal alcohol exposure on their child. One mother acknowledged "Sure, I thought about FAS when they asked me if I wanted Tina. But in my mind this meant she would have learning disabilities, which I was sure I could handle. I never realized that FAS meant *living*

disabilities" (Parent, personal communication, January, 1996)

Even families who are aware of the nature of their child's disability are often frustrated in their attempts to find appropriate services for their child. Fetal Alcohol Syndrome and Fetal Alcohol Effect are lifetime disabilities that affect every life domain, including the capacity for independent living. At this point in time, FAS is the leading cause of mental retardation in the United States, affecting approximately one in five hundred births. Fetal Alcohol Effect is estimated to be three times as frequent (Abel and Sokel, 1987). Despite these alarming statistics, there is no public policy to support these children and families, no organized effort to improve their lives. Some recent attention has been placed on prevention, an important goal, but of little value to individuals who already have the disability.

One reason for a lack of public policy may be difficulty in determining what social service should take the lead in providing support. FAS/E belongs in part to many programs, but does not clearly sit in any one. It is a concern of the mental retardation system, since it is now the leading cause of mental retardation in the United States. It is part of the mental health system both because of its connection to alcohol abuse and the significant behavioral issues associated with FAS/E. It is an educational issue because of the learning challenges it presents. It is a public health issue because it is a preventable disability. It is a medical issue because of the neurological damage and physical anomalies which characterize it. FAS/E is a child welfare issue because of the increasing number of children who enter care because of issues related to maternal substance abuse. Yet, no one system has stepped forward to take the lead in addressing the global needs of these children and their families.

Chapter III

Goals and Objectives

Having established the fact that foster and adoptive families of children with FAS/E are lacking important information and support, it became necessary to identify realistic goals which address these needs. The first three goals of this practicum were developed after consideration of the specific needs expressed by families who participated in the phone interviews. The fourth goal was formulated out of recognition that these supports cannot be time limited. Although the practicum period is of short duration, it is the author's hope that the supports created will continue beyond its time frame. In anticipation of the continuation of these efforts, the author has designated this program The Fetal Alcohol Support and Information Network of Southwestern Pennsylvania.

1. Goal - Agencies who provide foster care and adoption services will improve the quality and amount of information given to families prior to the placement of children who may have FAS/E.

1.1. Objective - Staff of at least four foster care and /or adoption agencies will demonstrate increased understanding of the characteristics of children with FAS through pre- and post- tests.

1.2. Objective - At least four foster care and/or adoption agencies who did not previously do so will include information about FAS/E in their parent training and preparation programs.

2. Goal - Parents who already have children with FAS/E in their home will be given an opportunity to learn more about the syndrome, its implications, and possible interventions.

2.1. Objective - Fifteen additional families that include children with FAS/E will be identified.

2.2. Objective - Information regarding FAS/E identification and intervention will be provided to identified families.

2.3. Objective - Information regarding FAS/E will be made available to a larger population of foster and adoptive families

3. Goal - Parents of children with FAS/E will develop a network of support and information sharing

3.1. Objective - Parents will communicate with each other on an individual basis.

3.2. Objective - Parents will develop a method for sharing information as a group.

4. Goal - Strategies for the continuation of these efforts at the conclusion of the practicum period will be developed

4.1. Objective - Funding sources will be identified.

4.2. Objective - A host agency will make a long term commitment to this effort.

Each of these goals was equally important to the success of this project. Agencies must understand the issues associated with FAS/E if they are to plan appropriately for the children in their care and prepare parents for the challenges they will face in raising these youngsters. In addition to accurate information, parents must have both personal and professional support as they encounter these challenges. These services should not be time limited, but should be available on an ongoing basis to families and professionals. While this project could not pretend to address all the needs of the families involved, it was viewed by the author as an important first step toward providing a continuum of information and support to those who need and deserve it.

Chapter IV

Solution Strategy

Review of Existing Programs, Models, and Approaches

In chapter one of America's Family Support Programs: Perspectives and Prospects (1987), Sharon Kagan and Alexandra Shelly identified groups for families of children with disabilities as one of eight most common types of family support programs. Anderson and Walsh (1988) emphasized the importance of such groups by describing an important role for family support programs that assist families with chronically ill or disabled individuals.

> There is an increasing awareness of the need to commit resources to the problems of families with chronically ill members, be the illness medical or psychiatric. Priorities should include (1) reduction of the stressful impact of chronic disorders on the family; (2) provision of information about the medical/psychiatric condition, patient abilities and limitations, and prognosis; (3) concrete guidelines for stress reduction and problem solving; and (4) linkage to supplementary services to support the efforts of families to maintain their patient members in the community. (p. 13)

Unfortunately, little commitment of resources has been made in Southwestern Pennsylvania to alcohol affected children or their families. As previously discussed, a contributing factor to this omission may be the confusion over which service sector is most appropriate to take the lead. As with many disabilities, the most effective advocates are the families of those who are affected

Birth parents of children with FAS/E are often overwhelmed with their own issues of substance abuse or struggling with the difficult task of recovery. Some are also dealing with guilt or denial over the nature of their children's disabilities (Hornby, 1993). These issues may complicate any effort to form a system of support for themselves or their children. In some cases, foster and adoptive parents, who are not dealing with these issues, may be more emotionally prepared to create supportive programs. Agencies who serve these families are logical partners in this effort.

In order for agency staff to provide effective support, they must have a clear understanding of the nature of FAS/E. A model for educating professionals at all stages of the adoption or foster care process was readily available. The adoption exchange which cosponsored this practicum has for many years offered monthly seminars on issues of importance to foster care and adoption agencies. Typically, between 40 and 50 professionals attend these meetings. In January of 1996, the author developed and presented a workshop entitled A Developmental Perspective of FAS/E to this group. As was customary, this workshop was announced in fliers which were distributed by mail to all member agencies. Despite inclement weather, almost 80 people attended this seminar. The presentation was well received, and evaluation forms were very positive. Many commented on the high quality of the handouts used in the workshop. The author was subsequently contacted by several agencies, requesting permission to copy and distribute the material presented. This model, an interactive workshop along with clear and concise printed material, appeared to be a practical and effective approach to meeting the first goal of the practicum.

This model for professional education was easily identified and chosen. The second, and more

time consuming, task was to review models of family support programs that might meet the expressed needs of foster and adoptive families.

There are many examples of programs that have been created by parents to support individuals with disabilities. The ARC is a nationally recognized group, providing a vast array of services and expertise to individuals with mental retardation and their families. Like many ARC chapters, ARC of Westmoreland County sponsors a Parent to Parent support group. Under the Parent to Parent umbrella there are several sub groups. These are distinguished by the area served, disabilities addressed, or age of the individual with mental retardation. These groups establish their own priorities, usually holding monthly support meetings. They share information with each other and the general public on issues of importance. Although individual groups do not publish a newsletter, the Westmoreland County ARC chapter distributes a quarterly publication, The ARChives. This newsletter includes contributions from any responsible group or individual and is available to all ARC members at no charge. The county ARC office also maintains a speakers bureau, and addresses many civic and professional organizations on issues related to mental retardation.

Another local group, Parents Helping Parents (PHP), was created to meet the needs of parents whose infants were being cared for in the Intensive Care Neo-Natal Units of area hospitals. This program hopes to reduce the stressful impact of infant hospitalization on the families involved. The group addresses this goal in two ways: an elaborate telephone support system and a monthly newsletter. PHP identifies families by distributing pamphlets and posters in all participating hospitals. Parents, who may also be referred by hospital social workers, are asked

to call a central number located in the program director's home. The program director speaks at length with each parent, learning the special needs of the child, the age of the parents, the area in which they reside, and other facts which may help in the selection of an appropriate support person. The director then refers to a list of over sixty volunteers, all of whom have children previously in a Neo-Natal Unit. These volunteers have participated in a six hour training on maintaining confidentiality and active listening. After being matched with a new parent, each volunteer provides a listening and supportive ear for the parent who is faces the emotional trauma of a critically ill infant. While the telephone system is their primary outreach, this group also publishes a small monthly newsletter. This newsletter may contain articles on medical breakthroughs in the care of premature infants as well as personal notes, such as hospital discharges or developmental milestones reached.

Although numerous other family support groups exist in Southwestern Pennsylvania, none respond specifically to the needs of families of children prenatally affected by alcohol. Such organizations do exist, however, in other parts of the country. The Family Empowerment Network (FEN) is based in Madison, Wisconsin and has achieved national recognition in only five years of existence. FEN was an outgrowth of a conference on perinatal substance abuse sponsored several years ago by the University of Wisconsin. Conference organizers were impressed by the number of parents who attended the conference and invited them to participate in their own sessions. From these meetings has grown a group that provides information and support to families across the United States. Their newsletter reaches thousands of families and agencies quarterly. Monthly teleconferences connect families throughout the United States and

Canada with experts in the field of FAS and related services. In addition, a full time program coordinator maintains regional lists of support programs, knowledgeable professionals, and key individuals to which callers may be referred. FEN also provides information packets containing several pamphlets and relevant articles upon request.

West Virginians for FAS Action began at the kitchen table of a foster parent in Flatwoods, West Virginia. While sitting with two friends, both of whom were foster and adoptive parents of children with FAS/E, the idea of holding a conference for similar parents and professionals was conceived. Women of action, they contacted agencies with likely concerns for this issue, such as the state Drug and Alcohol Council, asking for support and, most importantly, for money! The National Office of Substance Abuse Prevention expressed interest in their efforts, attending several planning sessions, as did Dr. Summer, a local pediatrician who became an outspoken advocate for their work. Less than four months after the idea was born, the first annual West Virginia FAS conference was held. It was attended by over three hundred people from across the United States. "People from the National Office..... said we could never pull it off that quickly. Finally, Dr. Summer remarked that if we did everything their way, they were probably right, it couldn't be done. If they would just let us do our thing, however, he was sure it would happen!" (Tina Hopkins, personal communication, February 18, 1996). The conference was just the starting point for this group. They now serve as speakers for agencies and parent groups throughout West Virginia. They are hoping to develop a camp program for children with FAS, as well as an FAS diagnostic center. They will be sponsoring their fourth conference this spring. Recently, they have been asked to conduct a research study in the West Virginia prison system to

determine how extensive FAS/E is among this population

Each of these programs has developed a unique approach to a shared concern, providing support to families and individuals with significant disabilities By studying these examples, considering the priorities suggested by Anderson and Walsh, and reviewing the needs expressed by the families interviewed, a family support system for foster and adoptive families of individuals with FAS/E could be developed in southwestern Pennsylvania

Proposed Solution Strategy

As a first step in creating such a support system, the author needed to present the proposed network to the staff of the adoption exchange cosponsoring this practicum The purpose was to provide them with appropriate protocols for any intake calls or questions regarding the network The author also proposed to meet with Tina Hopkins, co-founder of West Virginians for FAS Action, to review the material they distribute to families and to determine what could be included in this project

The goal of upgrading information given to parents by placing agencies was to be addressed first During the planning phase of this practicum, two agencies expressed an interest in scheduling staff training on FAS Other agencies in the area would be contacted, and the training offered to them at their site If individual agencies were unable to host the training, it would be offered at a neutral site, with staff from all agencies invited A minimum of four presentations was proposed The content and format was based on the workshop previously developed by the author To determine the effectiveness of the training, a pretest and a posttest developed by

West Virginians for FAS Action was to be administered to participating staff.

Fact sheets about FAS/E and its parenting implications were to be developed and distributed to all foster and adoptive agencies in the area. Agencies would be encouraged to distribute this information to prospective and current families. Follow up phone calls to these agencies were to be made at the midpoint of the practicum period to determine if the material was being used.

The second goal, which concerns providing information to parents of children with FAS/E was considered more challenging. The first objective in meeting this goal was to identify more families who are already parenting children with FAS/E. Several steps were proposed to contact such families. The first was to announce creation of the Fetal Alcohol Support and Information Network in adoption and foster parent newsletters throughout the area. Families would also be contacted through area newspapers. Using guidelines suggested in Bulletproof News Releases by Kay Borden (1994), a series of announcements were to be placed in community and urban papers. These releases would invite interested parents to call one of the two participating agencies to request information on FAS/E. All parents who did so were to be mailed an FAS/E information packet. They would also be invited to participate in parent supporting parent activities.

Many adoptive and foster parents are unaware that the children in their homes are suffering from FAS/E. An effort to reach these families was to be made through existing parent groups. The largest adoptive parent support group in the area, Council on Adoptable Children, agreed to run an article on parenting children with FAS in their April newsletter. A similar article was to be submitted to local ARC chapters for publication in their newsletters. If given more information

about the characteristics of children with FAS/E, the expectation was that parents would be able to recognize these traits in their affected children. Each article would include information about the support network, encouraging parents to call participating agencies for more information.

The third goal, parents helping parents, was essential to the success of this program beyond the length of this practicum. Families who participated in the documentation survey were clear in their desire to be in touch with other families, but equally clear in their resistance to traveling any distance to attend support group meetings. In order to provide local contact, the author proposed identifying "host families" in several areas of western Pennsylvania. These families were to organize an informational workshop in their community. The practicum student would conduct the workshops, the purpose of which was two fold. First, information on FAS and appropriate interventions would be presented. Second, parents who attended these presentations would be encouraged to stay in contact with each other. If they were interested in becoming a support group, additional technical and organizational support would be provided. Like the small Parent to Parent groups sponsored by Westmoreland ARC, each subgroup would be responsible for determining its own format for providing support. If parents were not interested in forming groups, they would be invited to share phone numbers and maintain contact informally.

Several parents who participated in the documentation survey expressed an interest in writing a newsletter for FAS parents. The practicum student proposed to meet with them, assisting them in publishing and distributing at least one issue during the practicum period.

The fourth goal identified in this practicum was perhaps the most important. The continuation of this network is essential if it is to have impact on the lives of the children and families it hopes

to support In order for an agency to offer a long term commitment to this program, a fiscal base needed to be established While the cost of community support groups could be covered by members, advertising and distributing material presents some expense Both participating agencies have expressed a commitment to maintaining the network, but mini grants or other sources of income needed to be identified Once again, families would be asked to participate in planning for continuation of this project A committee consisting of at least two parents and the practicum student was proposed to explore potential funding streams Once the interest of families and the ability to generate funds was demonstrated, on going support from the participating agencies seemed likely

The goals of this practicum were modest in relation to needs of families and children in Southwestern Pennsylvania The long term potential impact, however, is much greater Information and support for those affected by FAS/E can make a dramatic difference in the lives of children and the stability of their families

Chapter V

Strategy Employed

Action Taken and Results

In order to meet the goals of this proposal, a variety of tasks and approaches were necessary In addition to the objectives stated at the beginning of this project, several other opportunities for heightening awareness and understanding of FAS/E became available during the practicum period These opportunities, which will be discussed in this chapter, were incorporated into the structure of the Fetal Alcohol Support and Information Network

As proposed, the author met first with the staff of the adoption exchange, describing the program and developing a protocol for responding to inquiries An informative afternoon was also spent with representatives of West Virginians for FAS Action, gathering their ideas and suggestions In addition, the author met with Dr Leah Burke, a local geneticist who has studied with Dr Smith, the dysmorphologist who first identified Fetal Alcohol Syndrome The input from all these sources was very helpful in identifying the key points which should be addressed throughout the practicum

The first identified goal of the practicum was to improve the quality and quantity of information given by the placing agency to families who are considering parenting a child with FAS or FAE Clearly, information could not be given that was not available to agencies, so the first objective was to educate agency staff about FAS/E As proposed, two methods were used to provide critical information educational workshops and printed information packets

During the course of this practicum, workshops on FAS/E were presented by the author to four agencies. These workshops focused on the developmental course of this disability. Two of the workshops were presented to agency staff only, two presentations included foster and adoptive parents as well as staff. Pre- and posttests were included in the workshops. (Appendix D) These tests were designed by the student when the pre- and posttests developed by West Virginians for FAS Action could not be located by that agency. A total of thirty eight people attended the workshops. Seventeen completed and returned both test forms. Most of the other 21 participants did not take both tests because they arrived late, or left before completing the posttest. Twelve responses were from the sessions that included only agency personnel. The remaining five were from the sessions that included both parents and professionals. Unfortunately, the author did not ask the participants to identify themselves as parents or professionals on the test forms. As shown in Table One, however, all respondents demonstrated increased understanding of FAS/E. Most participants (approximately 70%) could distinguish between FAS and FAE prior to the workshop. All participants were aware of the difference after the presentation. Slightly more than half believed that an adolescent mother was more likely to have an infant with FAS than a middle aged woman. Of those who answered the question correctly, only five were able to explain that a woman with a longer history of alcohol abuse is more likely to have a child with FAS than a woman who has been drinking a shorter period of time. This puts the middle aged mother at higher risk. Following the presentation, 15 of 17 recognized that older mothers were more at risk, and 14 were able to explain why. Five participants were aware that FAS and FAE are estimated by experts to occur in four out of five hundred births. The twelve

who gave incorrect responses were equally divided between over and under estimating the frequency of the disability. Fifteen of seventeen were able to respond correctly following the presentation. Less than half of the participants could name three characteristics of FAS/E prior to the workshop, although everyone could name at least one. Following the workshop, 17 of 17 could name at least three markers. Prior to the workshop, only eight participants could name three intervention strategies for FAS/E children, although most could suggest one. In contrast, 15 participants could name three intervention strategies at the conclusion and everyone could name at least two.

Table 1

Increased Knowledge of FAS/E Following Presentations as Demonstrated In Pre and Post Tests

Question Number	Correct Responses Pretest	Correct Responses Posttest
1	12	17
2a	8	15
2b	5	14
3	5	15
4a	17	17
4b	13	17
4c	8	17
5a	16	17
5b	13	17
5c	8	15

Note. Questions 2, 4, & 5 required multiple answers. Each response was recorded separately.

The goal of presenting four training sessions during the course of this practicum was easily met. In addition, five other agencies have contacted the author to schedule workshops during the months of August and September. Encouraged by this positive response, the author submitted an outline of the workshop to the North American Council on Adoptable Children (NACAC), a international organization of parents and professionals in the field of adoption based at the University of Minnesota. Consequently, she has been asked to present the workshop this summer at the annual NACAC Conference in Dallas, Texas. An audience of approximately 150 parents and professionals is expected.

In addition to the workshops, an FAS/E informational packet specifically for foster care and adoption agencies was developed. (Appendix E) The material was developed by the practicum student with several considerations. First, the information needed to be clear, accurate, and specific to the concerns of foster and adoptive families. Second, the format needed to be easily copied for distribution to both agency staff and families. Third, it needed to be concise, since funds for mailing expenses were limited.

The information packet was distributed by mail to 48 adoption and foster care agencies in Southwestern Pennsylvania. Two weeks after distribution, follow up phone calls were made to 20 of the agencies to determine if the material had been received and how it was being used. The 20 agencies were selected for one of two reasons. To determine of the second objective of Goal One had been reached, four of the agencies who reported during the planning phase of this practicum that their agency did not routinely include information on FAS in parent preparation were contacted. The remaining sixteen agencies were selected because they were within the toll free

local call area. Of these twenty agencies, eighteen stated that they had already copied and distributed the material to staff and intended to use it in family training programs. Among these were the four agencies who, according to the prior survey, did not previously do so. This change by these agencies was one of the stated objectives of the practicum. Only two agencies did not feel that the information was pertinent to their needs.

The second goal of this practicum was to provide information on this disability to families who already have children with FAS. The minimum objective was to identify 15 families of children with FAS/E in addition to those who had already participated in the planning survey. As proposed, the student used several strategies to contact families. Using guidelines suggested in Bulletproof News Releases by Kay Borden (1994), a public service announcement was placed in 121 news outlets throughout western Pennsylvania. (Appendix F) This PSA announced the creation of the Fetal Alcohol Support and Information Network, and invited interested individuals to contact the participating agencies. A notice of the establishment of the network was also published in the newsletter of the Council on Adoptable Children (COAC), which is distributed to over 250 adoptive families. Notices were also sent to local ARC chapters for publication in their upcoming newsletters, although at the close of the practicum period, they had not yet been published. Thirteen families contacted the Network as a result of these efforts.

The second method of identifying families was through agency referrals. A letter suggesting that interested families be referred to the network was included with the information packet sent to agencies. Two formal referrals have been made through an agency.

The third method by which additional families were identified was through family referrals.

Two families were referred by other adoptive or foster parents who received information from the network.

The 17 newly identified families include eleven adoptive parents, two foster parents, a grandmother who had custody of her four year old grandson, and three birthparents. Families reside in five different counties of western Pennsylvania. One family lives in neighboring Ohio, and has been unable to locate resources in that state.

Parent packets were sent to each of the seventeen newly identified families, as well as to families who had participated in the original survey. These packets were similar to those distributed to agencies, although each had a different cover letter. (Appendix G) The author also made personal contact with all but one of the families, in several cases sending additional information specific to the families' needs. One birth parent preferred not to speak to me directly, and information was exchanged through a close friend of the parent.

The use of public service announcements brought about an unexpected positive outcome. The author was contacted by several agencies not previously identified. One agency, a treatment center for chemically dependent women, requested FAS prevention material. While the author was unable to provide such material, she was able to refer the caller to the National Organization on Fetal Alcohol Syndrome (NOFAS), a national FAS prevention group. A second contact was from a hospital social worker in eastern Pennsylvania who counsels parents of children in the neo-natal intensive care unit. She requested additional information in order to better meet the needs of clients she believed to be at high risk for FAS. The third unsolicited agency contact was from the newly formed Pennsylvania Special Kids Network. This statewide program has been created to

link the families of children with a variety of exceptionalities with appropriate resources and support. The Fetal Alcohol Support and Information Network will be now be included in a statewide directory as an ongoing resource for families.

Two school programs also contacted the practicum student, requesting information and suggestions on developing appropriate educational programs for affected students. The author was also asked to participate in a television news feature on the CBS affiliate in the Pittsburgh market. This feature, Woman to Woman, described the cause and effects of Fetal Alcohol Syndrome and was broadcast on multiple occasions.

Broadcast of the news feature helped make information about FAS and FAE available to a larger population, another program goal. The author also wrote an article about FAS which was published in the June issue of the Council on Adoptable Children newsletter. This article, "FAS/E - General Information for Adoptive/Foster Parents" was included in the agency packets and can be seen in Appendix D.

The third goal of the practicum experience was to provide an opportunity for parents of children with FAS to create a network of support and information sharing. In the original proposal, the identified strategy was to assemble small groups of parents for informational meetings. This approach proved to be unsuccessful. Three host families were identified, but only two actually scheduled meetings during this period. Both were subsequently canceled due to lack of response from the community. This outcome should not have been surprising, since the preliminary survey indicated that most families were not interested in attending group meetings. It was, however, disappointing, since it did not provide an opportunity to reach parents whose

children had not yet been diagnosed with FAS/E. The author adjusted to this outcome in two ways. First, as mentioned, the workshops scheduled by two of the agencies were modified to include parents as well as staff. At each of these workshops parents were encouraged to share names and phone numbers with other participants. Second, the author met with or spoke at length on the phone with each identified family. With each party's permission, she then shared the name and phone number of a parent who was dealing with similar issues. This approach, which was based on the Parents Helping Parents Model previously discussed, more accurately reflected the needs expressed by families in the preliminary survey. Although the strategy needed to be changed mid course, the desired outcome, parents communicating with each other, was met.

Parents also shared information through FAS Talk, the newsletter that grew out of this practicum. (Appendix H) The first edition of FAS Talk was distributed to over seven hundred families and agencies on the exchange mailing list, as well as to families who had been identified through the course of the practicum. It was written by a participating parent, with input from Dr. Leah Burke and the practicum author. The practicum author has contacted the local chapter of the March of Dimes to request funding to continue the publication of this newsletter. In cooperation with the parent author, an editorial board has been established and a grant proposal has been submitted. The local grant coordinator for March of Dimes has responded favorably to preliminary information and has indicated that the funds will be made available.

This grant proposal is an important step in meeting the final objective of this practicum experience - that of sustaining the efforts begun during these ten weeks. Both of the agencies that cosponsored this practicum will continue to serve as host agencies for the Network. In addition,

the adoption exchange has offered the continued use of office equipment and desk space. The practicum student will continue to coordinate the Network. Mailing expenses will be covered by charging fees to agencies who schedule workshops. The adoption exchange has also agreed to work with the author in creating and submitting additional grant proposals which would provide additional funding for the Network.

Several exciting long term possibilities for continuation of this program have also emerged. These involve the expansion of services offered and are discussed in the next chapter.

Chapter VI

Conclusion

Implications and Recommendations

The creation of the Fetal Alcohol Syndrome Support and Information Network of Southwestern Pennsylvania has begun to address a critical need in this area. Although midcourse changes in strategies were occasionally required, all the proposed goals and objectives have been met or exceeded.

Response to the material distributed to parents and professionals has been overwhelmingly positive. This material will continue to be available as requested. Several foster care agencies who also provide birth family support services have suggested that the focus of the network be expanded to include all families that include children with FAS/E. They have also requested information on working with adults with FAS/E, since they suspect many of the birth parents with whom they work may themselves be affected. It is the recommendation of the practicum student that the Network be expanded to include all families touch by Fetal Alcohol Syndrome or Effect. In order to appropriately meet the needs of birth families, the Network should work closely with alcohol treatment programs and recovery groups.

Identification of individuals affected by prenatal alcohol exposure should continue to be a high priority. The concept of community based informational meetings, although not successful during this practicum experience, should be reevaluated. It is possible that this approach would be

successful with increased attention to advertising and promoting the meetings

The lack of effective educational and vocational programs for individuals with FAS/E was frequently sited by program participants. A long term goal of The Fetal Alcohol Support and Information Network could be to work cooperatively with special education programs and the Office of Vocational Rehabilitation to develop strategies which would address issues specific to individuals effected by prenatal alcohol exposure.

Two local medical facilities have contacted the practicum student to discuss establishing an FAS program within their institutions. One is an established rehabilitation facility that specializes in serving clients with brain injuries. Physical, occupational, speech, and sensory integration therapies are all available through this facility. In addition to both in and outpatient facilities, this facility includes a day school program for exceptional students. Its model of specialty care would be ideal to serving this population. Discussion is still preliminary, but the Network may serve in an advisory capacity should the facility decide to establish this program. The author already has a working relationship with this facility, since it housed the adoption agency at which the author was previously employed.

The genetics department of a large local hospital has also expressed interest in establishing an onsite FAS clinic. This clinic would provide FAS screening and diagnostic information to individuals and families. Referrals would then be made to appropriate services, including the Network. Contact with this hospital has been made through Dr. Burke, who has served in an advisory capacity throughout this practicum.

The March of Dimes has also expressed an interest in expanding its involvement with this

program. In order to be eligible for significant funding from this, and indeed most grantors, the Network would need to be incorporated as a non profit organization. An advisory board has been created to begin this process. The advisory board includes two adoptive parents of children with FAS who work in non related fields, one adoptive parent of a two young adults with FAS who works in a support program for families in crisis, an adoption professional, and the practicum student. In addition to the process of identifying the Network as a non profit organization, this board will determine the long range goals of the Network. Many directions are possible. Case management, advocacy, educational and vocational training, prevention, behavior management, consultation are all possible roles the Network could play.

One service the Network must continue to provide is individualized support to families who are facing a tremendous challenge. It is recommended that the Network continue to provide this level of service to all families who contact the program.

The work begun through the practicum has addressed a previously unmet need in western Pennsylvania. It has been an exciting process to begin this effort and to witness the enthusiasm with which it has been received. As both a parent and a professional, the practicum student is firmly committed to its continued existence.

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Appendix A

December 20, 1995

Dear friends,

Did you know that Fetal Alcohol Syndrome is now recognized by Public Health officials as the leading cause of mental retardation in the United States? As adoptive and foster parents, many of you have first hand knowledge of the difficulties encountered by children who have Fetal Alcohol Syndrome and Fetal Alcohol Effect. Even among those who do not have mental retardation, the educational and behavioral issues these children confront are often overwhelming.

In cooperation with Three Rivers Adoption Council, I am conducting a study of adoptive and foster families who include a child with FAS/FAE. The purpose of this effort is twofold. The first goal is to determine if families are adequately prepared for the adoption of children with this specific disability. The second is to determine if families are receiving the type of information and support they need to parent their children effectively after placement. Information gained from this study will be used as part of a Master's Practicum through Nova Southeastern University. In addition, it will be used as a guideline in improving services to local children and families effected by FAS/FAE.

I am asking for your assistance in this study. If you are the parent of an adopted or foster child with FAS or FAE, please contact Three Rivers Adoption Council at (412) 471-8722. Leave your first name and a phone number, stating that you are willing to participate in the FAS study. Your call will be returned in mid January, at which time you will be asked to spend about fifteen minutes responding to a brief, confidential survey. The survey will discuss the preparation and information you received prior to placement, the support you are currently receiving, and the services you believe would benefit your child. If you wish, you will also be placed on a mailing list to receive the results of this survey and additional information on FAS/FAE.

Thank you for your interest in this study. It is my hope that it will be an important step toward meeting the needs of those touched by this unique disability.

Sincerely,

Mary Pat Zebroski

Appendix B

Parent Survey

As part of the practicum proposal a telephone survey has been developed to identify areas of need for foster and adoptive families in Southwestern Pennsylvania that include a child or adolescent with FAS/FAE. Participants will be identified through voluntary response to a letter distributed by a large family service agency in the Pittsburgh area. The interview will be conducted by phone by the practicum student. It is expected to take approximately twenty minutes to conduct, however, additional time will be spent with participants who desire more information or wish to discuss their responses in detail.

The first few minutes of the telephone interview will be spent providing information to the participant. The author will introduce herself as an adoptive parent, a professional in the field of foster care and adoption, and a graduate student at Nova Southeastern University. The author will explain that the survey is the initial phase of a practicum project. Results of this survey will be used to identify a focus area for continued development. Ultimately, this should lead to an improvement in services to children with FAS/FAE and their families.

After these introductory remarks, the survey will be conducted. The survey itself will focus on three key issues. The first is to determine if families are being offered adequate information prior to the placement of children with FAS /FAE into their homes. The second issue which will be explored is the nature of support services made available to and used by families after children with FAS/FAE were placed with them. The third area of discussion will be to determine what services families believe would benefit both their children and their families. After the survey has been completed, there will be a brief wrap up.

I. Introductory Information

Do you have a child in your home who has been diagnosed with FAS/FAE?

___ **no** Thank caller for interest, but explain survey is only for children already diagnosed

___ Do you suspect your child may have FAS/FAE?

___ Would you like more information about FAS/FAE?

___ Would you like to receive information about the outcome of this project?

___ **yes** Continue with survey

II. Placement Information:

How old was your child at the time of placement? ___

How old is your child now? ___

Had the diagnosis of FAS/FAE been made prior to placement?

___ yes - child was diagnosed before placement

Did the agency who placed the child in your home provide you with information regarding FAS/FAE?

___ no

___ yes - continue

What information were you given?

_____

_____

_____

_____

_____

Was the information part of your decision making process?

___ yes

___ no

In your opinion, was the information accurate?

___ yes

___ no

In your opinion, was the information thorough?

___ yes

___ no

____ no - child was not diagnosed before placement

Did the agency who placed the child in your home discuss the possibility of FAS/FAE?

____ yes

____ no

Did they provide you with information regarding maternal drinking or other substance abuse?

____ yes

____ no

Was the information part of your decision making process?

____ yes

____ no

III. Post Placement Services

Is the agency that placed your child with your family aware of your child's diagnosis?

____ yes - the placing agency is aware

Since the time of placement, has the placing agency offered additional information on FAS/FAE?

____ yes

____ no

____ no - the placing agency is not aware

Did the behavioral issues associated with FAS/FAE ever jeopardize your child's placement in your family?

____ yes

____ no

Please elaborate_____

_____

_____

_____

_____

_____

_____

_____

Have any of the following services been offered to your child and/or your family?

OU - Offered and used ON - Offered but not used N - Never offered

_____ Subsidy
_____ Medical Assistance Card
_____ Educational advocacy
_____ Respite
_____ Behavioral management consultation
_____ Family counseling
_____ Job coaching
_____ Independent living skills training
_____ Additional information on FAS/FAE

Has the placing agency offered any other type of support related to this child's disability?

___ yes
Please elaborate _____
_____
_____
_____
_____

___ no

Has any other agency been particularly helpful to your child and your family?

___ yes
Please elaborate _____
_____
_____
_____
_____

___ no

IV. Services Needed or Desired

Do you believe that your child would benefit from any of the following

_____Subsidy
_____Behavioral management consultation
_____Educational advocacy
_____ Job coaching
_____Independent living skills training
_____Supervised recreational activities
_____Information about his/her disability
_____Other

Do you believe your family would benefit from any of the following?

_____Subsidy
_____Behavioral management consultation
_____Family counseling
_____Respite
_____Additional information about FAS/FAE
_____Support group
_____Other

The author will conclude the interview by thanking the participant and assuring them of the confidentiality of their answers. The author will offer the participant the opportunity to be on a mailing list to receive the results of the survey and additional information on FAS/FAE. If the participant desires to receive this information, name and address will be taken. This information will be recorded separately from survey responses.

Appendix C

Dear Colleagues,

Three Rivers Adoption Council and BTM Resources are interested in learning what type of information and support is needed by foster and adoptive families of children with Fetal Alcohol Syndrome and Fetal Alcohol Effect. In order to learn more about services already available to these families, I am asking the senior staff person of each agency in attendance to answer these brief questions. Feel free to comment or make suggestions, but please return only one form per agency. Thank you.

Mary Pat Zebroski
BTM Resources

Agency Name (optional) _____

Does your agency routinely provide information about FAS/E as part of the parent preparation process for foster/adoptive families?

Has your agency provided professional training to staff on FAS/E within the past two years?

Does your agency provide any postplacement services specific to this disability? If yes, please describe

Appendix D

FAS/FAE: WHAT DO YOU KNOW?

1. What is the difference between Fetal Alcohol Syndrome and Fetal Alcohol Effect?

_____

_____

2. Is a teen mom more or less likely to have a child with FAS than a middle aged mom? Why?

_____

_____

_____

3. How frequently do FAS and FAE occur in the general population?

___ One in one thousand births ___ Four in five hundred births ___ Three in one hundred births

4. Name three characteristics of FAS

_____

_____

_____

5. Describe three strategies that assist an individual with FAS

_____

_____

_____

Appendix E

Dear colleague,

As you perhaps know, Fetal Alcohol Syndrome and Fetal Alcohol Effect are the most common birth related disabilities in the United States today. Many experts believe that as many as four in five hundred children will experience a lifetime of disability as a result of prenatal alcohol exposure. More than half of these children will spend a part of their childhood in substitute care, most often kinship, foster, or adoptive families. It is imperative that agencies such as ours are knowledgeable about FAS and FAE, so that we can effectively support parents who assume responsibility for these children.

Three Rivers Adoption Council and BTM Resources have established the Fetal Alcohol Support and Information Network to improve the quantity and quality of information on FAS/E which is available to parents and professionals. Enclosed you will find several articles and fact sheets which you may find helpful in preparing parents for the possibility of raising a child with Fetal Alcohol Syndrome or Fetal Alcohol Effect. Please feel free to duplicate the material for distribution to your families.

The Network is also developing a locally based newsletter and support network for families of children with FAS/E. If you would like to refer a family to our mailing list, please contact me at the TRAC office (471-8722) or at BTM Resources (733-8782).

A two hour training opportunity for staff and parents is also available through BTM Resources. This presentation provides an overview of the developmental path of FAS/E, highlighting both concerns and strengths and providing suggestions for successful parenting. Information regarding available dates and fees is available through BTM Resources.

I hope you will find the enclosed information helpful. Your comments and suggestions would be greatly appreciated.

Sincerely,

Mary Pat Zebroski
Director
BTM Resources

FAS/E - General Information for Adoptive/Foster Parents

Lack of information and support to an adoptive or foster family of a child with Fetal Alcohol Syndrome or Fetal Alcohol Effect can complicate the already difficult task of integrating a new member into an existing family. In her landmark article for The Atlantic Monthly, "Problem Adoptions", Katharine Davis Fishman (1992) succinctly summarized what families and agencies have found to be true. "When adoptions come to grief, it is often from a disparity in expectations: either the parents expected something the child can't deliver, or the child delivers something the parents didn't expect!" This is never more compelling than in the case of a family who has adopted or is providing foster care for a child with FAS/E and who has been given inadequate information about its impact. Diane Malbin, well known author and parent of a child with FAS states simply "Trying to raise a child with undiagnosed FAS is like trying to get around Cincinnati with a road map of Denver". Even after a child has been diagnosed with FAS/E, parents may not be aware of the specific behaviors accompanying this diagnosis. They may still be unprepared to deal with the needs and challenges of the child they are raising. In order to recognize the importance of information and the nature of supports that must be made available to families of children with FAS/E, it is necessary to first understand the pervasive nature of the disorder itself.

Fetal Alcohol Syndrome and Fetal Alcohol Effect are a collection of symptoms that can result when a developing fetus is exposed to ethanol, the primary intoxicant in alcoholic beverages. Since the fetus lacks the enzyme alcohol dehydrogenase, which metabolizes alcohol, alcohol can quickly reach toxic levels in the fetus. Complicating this is the immaturity of fetal liver and kidneys, which are unable to quickly break down and excrete the alcohol. The resulting prolonged exposure to a depressant can have a profound impact on the developing fetus. FAS is chiefly characterized by abnormalities in three areas: the face, somatic growth, and the brain. Children who have been diagnosed with Fetal Alcohol Effect do not have the facial or growth abnormalities associated with FAS, but have experienced the brain damage and demonstrate its effects.

The face of FAS is characterized by a series of abnormalities that form a "T" within the face. The horizontal axis is formed by the eyes. In a typical facial structure, the length of each eye slit is roughly equivalent to the distance between the inner corners of the eyes. In a child with FAS, the distance between the eyes may be up to 50% greater than the length of the eye openings. In addition, some children with FAS have epicanthic folds (skin covering the corner of the eye) or ptosis (drooping) of the eye lid. Along the vertical axis, consideration is given to the nose, midface, and lips. In FAS the nose is slightly shorter than the norm in comparison to midface length and the area adjacent to the nose may have a flat appearance. The philtrum (the vertical

groove between the nose and upper lip) is shallow and the upper lip is thinned. The facial characteristics of the vertical bar become less obvious in adolescence. To assist in the diagnosis of an adolescent or adult, a photo from early childhood may be necessary. Unfortunately, many children in foster care or adoption do not have early photos available to them.

Somatic growth deficiencies are generally considered to be the least reliable indicator of FAS. They can be used to support a diagnosis, but normal growth pattern does not rule out a finding of FAS. Children with FAS usually have low birth weight and remain below the tenth percentile for both height and weight until puberty. At this time, a growth spurt may improve the height centile. Growth deficiencies in FAS are not associated with poor nutrition or hormone deficiencies, so are not generally treatable.

The last diagnostic criteria for FAS is a specific pattern of brain damage. Evidence of brain damage is not simply inferred through observation of affected individuals. Autopsy studies of children with FAS and FAE reveal clear and extensive neurological damage.

Damage to the brain may be structural, neurological, and/or behavioral. Structural abnormalities are least common. They may include microcephaly, hydrocephalus or structural anomalies of brain matter. Neurological damage includes a number of symptoms. These may be abnormal EEG patterns, tremors or poor coordination, abnormal muscle tone (hypertonia or hypotonia) and vision and hearing def·its. Parents should be aware of all of these possibilities, since early intervention and medication may ameliorate these conditions.

The behavioral implications of Fetal Alcohol Syndrome and Fetal Alcohol Effect can be a source of frustration to many parents. Many of the behavioral and educational difficulties presented by children with FAS/E can be perceived as willful disregard for parental values and expectations. Others are more clearly recognizable as symptomatic, but are equally frustrating. They include, but are not limited to, the following.

1. Reduced IQ performance. Many individuals with FAS/E fall within the range of mental retardation, although IQ in the low average or borderline range are most common. This places many children with FAS/E in a grey service area, unserved by the mental health / mental retardation system and often not well served in the special education system. Parents are often frustrated in finding therapists or educational programs that meet the needs of their children.

2. Attention deficit disorder, with or without hyperactivity. Families whose emotional commitment to the child is just developing often find the activity level of the ADHD child very difficult to accept. Children with ADHD are often intrusive and can be both destructive and aggressive. Children whose attention deficits are not accompanied by hyperactivity can go unnoticed and unassisted in classrooms for years. A child who has FAS/E is not a good candidate for inclusion, requiring small classes with fixed routines for optimal learning. Classroom

adaptations that focus on restructuring the environment seem to have the most favorable impact.

3. Learning disabilities. Many people have a learning disability in one or two areas. Children with FAS/E seem to have processing deficits in all areas. They have trouble recording, interpreting, storing, retrieving, and using information. Many children will function well one day and poorly the next. Arithmetic is often the most problematic area and as a result many children will never learn to tell time or make change. Even for children who are able to read a clock, the concept of time remains vague. These basic skill deficits often compromise the ability to function independently in adulthood.

4. Speech and language delays. Although children with FAS/E are usually delayed in acquiring speech, they become quite "chatty" in early childhood. Often times they impress casual acquaintances with their vocabulary and inquisitive nature. Unfortunately, this seeming verbal skill camouflages lack of depth in conversation and difficulty recalling stories or events in any detail. The questions asked by children with FAS/E tend to be repetitious and center on a few perseverating themes.

5. Problems with reasoning and judgement. Parents of children and adolescents with FAS/E find this aspect of FAS/E to be especially troublesome. Individuals with FAS/E experience unusual difficulty with problem solving, generalizing information, and controlling their own behavior. Difficulty in learning from experience and planning for the future are common.

A family who understands the nature of FAS/E is better able to provide what their child needs than one who is unprepared. Predictable routines, clear expectations and supervision beyond that dictated by chronological age are all necessary parenting demands. Because of the child's appearance of competence, parents are often viewed by unknowledgeable professionals as overprotective or unduly rigid. Without support, these parents can become frustrated and less effective as they find themselves dealing not just with their child's disability, but a lack of understanding on the part of service providers.

The responsibility of raising a child with Fetal Alcohol Syndrome or Fetal Alcohol effect is tremendous. Despite heroic efforts on the part of many parents, the outcome for their children remains uncertain at best. Recent studies suggest, however that early identification, intervention, and support can greatly improve the individual's chances for success. There is no doubt that a child whose life has been altered by prenatal exposure to alcohol finds his best hope for a productive adulthood in the circle of a committed and caring family. If you would like more information about Fetal Alcohol Syndrome, please call the Fetal Alcohol Support and Information Network, sponsored by Three Rivers Adoption Council (471-8722) and BTM Resources (733-8782).

FAS/E - Important Facts

1. Fetal Alcohol Syndrome has become the most common f .m of mental retardation in the United States. FAS occurs in about one in five hundred births. FAE is about three time more frequent. Almost two thirds of the children born with FAS/E each year will spend part of their childhood in substitute care!

2. Fetal Alcohol Syndrome includes a number of physical characteristics, as well as predictable educational and behavioral differences. Individuals with Fetal Alcohol Effect demonstrate the same behavioral and educational challenges, but do not have the facial or structural indicators of FAS.

3. The facial anomalies associated with FAS include a flat midface, shallow philtrum, thin upper lip, ptosis, and a small, upturned nose.

4. Children with FAS usually have low birth weight. Because they gain weight slowly, they are sometimes diagnosed as failure to thrive infants. Children with FAS usually remain small for their age through adolescence, although they grow at a constant rate.

5. The most troublesome aspects of FAS/E are difficulties in abstract reasoning and skill retention. This leads to poor judgment, inappropriate social behavior, and diminished capacity for independent living.

6. Individuals with FAS/E are often extremely outgoing and talkative. Because of this they can project an false impression of competence. It is not uncommon for individuals with FAS/E to find themselves in jobs or social situations for which they are lacking skills.

7. Children with FAS/E experience developmental delays and difficulties in all life domains. The effects of prenatal expose to alcohol are never out grown, but early identification, appropriate interventions, and a supportive family environment may help individuals overcome their disability.

8. There are no **easy** methods of raising a child with FAS/E. Some methods, however, are more **successful** than others!

Hints for Parenting a Child with FAS/FAE

1. Always remember: FAS/FAE are disabilities, not simply behavior problems.
2. Try differently, not harder. If one approach does not work with your child, try another!
3. Use as many concrete methods of organization as possible. Lists, pictures, rhymes, and routines help the child navigate through the day.
4. Begin teaching important life skills early, and continuously reinforce them.
5. Speak to your child calmly and directly. Yelling and lecturing will only confuse him or her. Children with FAS/E need extra time to process auditory information. They are also often hypersensitive to noise, so a raised voice can be distracting from the message.
6. Make sure your child receives the appropriate evaluations and therapies. Physical therapy, occupational therapy, speech therapy, and sensory integration are often necessary.
7. Do not allow your child to become overly frustrated. Most experts agree that frustration and low self esteem are the roots of the behavior problems noted in FAS/E adolescents and adults.
8. Learn as much as you can about FAS and FAE. Teach others who work with your child about it as well.
9. Recognize that your child's emotional, intellectual, and physical development will all be delayed. Don't expect your child to "act her age". Enjoy having a "little kid" for as long as you can!

10. Accept and cherish your child for who she is, not who you wish she was!

Questions to Ask Yourself Before Adopting a Child with a Possible Diagnosis of FAS/E

1 Do I believe that FAS and FAE are **real** disabilities?

2 How frustrated will I be if this child demonstrates the learning and judgment impairments characteristic of prenatally exposed children?

3 Is my extended family supportive of this adoption? If not, can I place this child ahead of my relationship with them?

4 Am I willing to deal with special education, mental health, and juvenile justice systems if necessary?

5 Am I able to provide the daily structure that this child will need to function most effectively?

6 Will I be able to remain calm when this child behaves inappropriately in public?

7 What are my long term goals as a parent?

8 Am I willing to be a support person for this child throughout his adulthood?

9 Can I love and cherish this child no matter how difficult he is to raise?

Appendix F

PUBLIC SERVICE ANNOUNCEMENT

SUBJECT Fetal Alcohol Syndrome

RELEASE Immediate

CONTACT Mary Pat Zebroski
Fetal Alcohol Support and Information Network
Three Rivers Adoption Council
(412) 471 - 8722

Fetal Alcohol Syndrome is now the most common birth defect in The United States. Both FAS and its related disability, Fetal Alcohol Effect, can affect an individual's ability to learn, to behave in an age appropriate manner , and to maintain employment. If you are the birth, foster, or adoptive parent of an individual who was prenatally exposed to alcohol and who is experiencing learning or behavioral problems, contact the Fetal Alcohol Support and Information Network at the Three Rivers Adoption Council (471-8722) to learn more about Fetal Alcohol Syndrome

Appendix G

Dear friend,

Welcome to the Fetal Alcohol Support and Information Network! This network has been created by BTM Resources and Three Rivers Adoption Council in response to the needs of foster and adoptive families that include individuals whose lives have been altered by prenatal alcohol exposure. The goal of the network is three fold. The first goal is to provide child placement agencies with improved information regarding the nature and frequency of this disability, so that they are better prepared to recognize affected youngsters and plan appropriately for them. Information packets have been distributed agencies throughout the area. In service trainings have also been provided to several agencies, with more planned for this fall.

The second goal is to provide information and support to families that already include a child with Fetal Alcohol Syndrome or Effect. The enclosed information packets are available by contacting TRAC (471-8722) or BTM Resources (733-1996). We hope to distribute other material as it becomes available. Your name is currently on the information mailing list. If you prefer not to receive additional material, please contact me at 733-8782. We are also available to meet with you individually , as well as to make presentations to groups who may be interested in learning more about FAS/FAE. Please contact me at BTM Resources (733-8782) for more information regarding individual consultation and speaking engagements.

Thirdly, we hope to establish a network of families who can be of support to each other. Please contact me if you would like to speak to another parent, or are willing to be a support to others. You will also find in this packet the first issue of FASTALK, a parent generated newsletter that will be distributed through the Network.

I hope you will find the enclose information helpful. Your ideas and suggestions are welcome!

Sincerely,

Mary Pat Zebroski
Director
BTM Resources

Dear friends,

Thank you for your recent participation in the needs survey of foster and adoptive families that include an individual with FAS or FAE. Your responses illustrated several important issues for families in Western Pennsylvania. Many of you indicated that you had not been made aware of your child's diagnosis before their placement in your home. While only one of you felt that information had been deliberately withheld, all of you felt that having an appropriate diagnosis from the beginning of placement would have contributed significantly to your family's ability to provide for your child. Among those of you who had been given a diagnosis, some of you believed that the impact of FAS and FAE on an individual's life had been minimized by the placing agency. Most of you expressed a need for both information and services specific to this disability. In many cases, traditional parenting and educational techniques are not effective for children with FAS/E. Support for your families is not readily available and service providers often do not recognize the pervasive nature of this disability.

As a result of this survey, BTM Resources, in cooperation with Three Rivers Adoption Council, has created the Western Pennsylvania Fetal Alcohol Support and Information Network. The goal of the network is three fold. The first goal is to provide child placement agencies with improved information regarding the nature and frequency of this disability, so that they are better prepared to recognize affected youngsters and plan appropriately for them. Information packets have been distributed agencies throughout the area. In service trainings have also been provided to several agencies, with more planned for this fall.

The second goal is to provide information and support to families that already include a child with Fetal Alcohol Syndrome or Effect. The enclosed information packets are available by contacting TRAC (471-8722) or BTM Resources (733-1996) We hope to distribute other material as it becomes available. Your name is currently on the information mailing list. If you prefer not to receive additional material, please contact me at 733-8782. We are also available to meet with you individually , as well as to make presentations to groups who may be interested in learning more about FAS/FAE. Please contact me at 733-8782 for more information regarding individual consultation and speaking engagements.

Thirdly, we hope to establish a network of families who can be of support to each other. While many of you expressed a need to speak with other families of children with FAS/FAE, you also indicated that the demands of parenting made attendance at regular support group meetings

difficult. Your preference was an informal "buddy system" of parents of children of similar age. Please contact me if you would like to speak to another parent, or are willing to be a support to others. Some of you also expressed an interest in a locally based newsletter, the first issue of which is enclosed.

Once again, thank you for you participation. I hope that the Network that has been established as a result of your input will be of service to you for many years to come.

Sincerely,

Mary Pat Zebroski
Director
BTM Resources

Fetal Alcohol Syndrome

FAS Talk

p 73

FAS/FAE Parent Newsletter May, 1996

Welcome

Welcome to the first issue of FAS Talk, a newsletter primarily for parents of children with Fetal Alcohol Syndrome and Fetal Alcohol Effects. As parents of children with FAS/FAE we are painfully aware that there is a lack of support systems for parents and children with FAS/FAE in this area. Our hope is that through this newsletter we can develop a support system, share information, stimulate thinking, and create a network of individuals interested in this topic who will help us to help our children reach their greatest potential.

We encourage your participation and feedback. Let us know what you think, what you would like to see included and any questions you have.

We can be reached at:
FAS Talk
BTM Resources
2785 Walker Drive
Export, PA. 15632
phone: (412)-733-8782
e-mail: lil barrel@aol.com

A Parent's Thoughts

I know that a child with FAS is not an easy child, and as parents it's difficult sometimes, and... we worry about the future. We get tired of difficult behaviors and ask ourselves if we did anything to create the acting out, the aggressive and uncontrollable outbursts and when will this end. We know that routine is the safest road to peace, changes in routine precipitate anxiety and loss of self control but change in routine happens all the time especially when we have other children who require attention.

We realize that we have to be patient, firm and consistent and above all affectionate. Our children, not unlike other children, need to feel loved. They appreciate positive reinforcement. But we must understand their limits and respect them and give them the help they need to function in the world. Positive expectations are important and negative expectations hurt parents and children. Our children have many talents and with guidance and love they will have a very positive life.

Fetal Alcohol Syndrome

In the early 1970's, particular physical, mental and behavioral characteristics were noted in some children born to women who drink alcohol during their pregnancies. This pattern of features is now known as Fetal Alcohol Syndrome or FAS, and alcohol was recognized as a teratogen or a substance that causes birth defects.

Children with FAS are usually smaller at birth and often have problems with growth after birth. This causes them to be short and to have small heads. Their facial features are distinct, and therefore they may have a different facial appearance than other members of their family. The distinct facial features include small eyes, sometimes with droopy eyelids, and a smooth area above the upper lip with a thin upper lip. They also tend to be a little flattter through the area of the cheekbones. Of the internal birth defects seen in children with FAS, heart defects are the most common, but cleft lip and palate as well as small fingernails, joint

abnormalities and brain abnormalities have also been seen.

Even in the absence of obvious structural brain defects, children with FAS have learning problems which vary from frank mental retardation to specific learning problems, such as delays in motor and speech development. In addition, children with FAS have problems with hyperactivity and attention deficit disorder, as well as impulsive behaviors. These behavioral problems can cause lifelong difficulties even for children with FAS who otherwise have borderline intelligence.

Some children exposed to alcohol during pregnancy do not have the physical characteristics to give them the diagnosis of FAS, but still have the learning and behavioral problems. Sometimes these children are referred to as having FAE or Fetal Alcohol Effects.

In order to make the diagnosis of FAS, a child should have an examination by a physician who is familiar with the condition.

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Book Review

Fantastic Antone Succeeds - Experiences in Educating Children with FAS. J. Kleinfeld & S. Wescott, ed.

This is a collection of success (yes, success) stories of children with Fetal Alcohol Syndrome and their families. Each chapter tells the story of a specific family or program that has made a positive impact on the lives of children with FAS and FAE. While realistic in its portrayal of the difficulties encountered by these children, this book offers hope for their future. Early diagnosis and educational strategies that build on the unique talents of every child are the keys to success. If you have only one book on FAS in your home, this should be it!

It is available from the University of Alaska Press, 1st Floor Gruening Bldg. UAF, Fairbanks, Alaska 99775, (907) 474-6389 for $23.50, which includes shipping and handling, or from Special Needs Project, 3463 State Street, #282, Santa Barbara, California 93105, (800) 333-6867 for $20.00 paperback, or $30.00 hardcover plus $4.00 for shipping and handling.

Summer Recreation

The Children's Summer Sports Program at the University of Pittsburgh Trees Hall is a developmental sports program for children between the ages of 3 to 12 years. The program is divided into two parts: gym and swim. All children have one hour of instruction in swimming and one hour of instruction in the gym. For more information call: Jere Gallagher, PhD, (412) 648-9183 or Rose Pompura, (412) 648-8266

Resources

A resource for free or minimal cost information on materials related to drug and alcohol and their effects. They also do literature searches.

National Clearinghouse for Alcohol and Drug Information (NCADI)
P.O. Box 2345
Rockville, Maryland 20847-2345
tel: (301) 468-2600
(800) 729-6686

Publications available on fetal alcohol syndrome.

Fetal Alcohol Education Program
Boston University School of Medicine
7 Kent Street
Brookline, Massachusetts 02146
(617) 739-1424

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